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ABSTRACT

Thirty-two individuals with cancer or HIV (human immunodeficiency virus) were interviewed concerning their employment related experiences and concerns. Findings indicated that the decision to tell their supervisor and/or co-workers about their health status varied substantially between individuals with HIV and those with cancer. All study participants with cancer disclosed to their employer and co-workers whereas only a third of those with HIV infection told everyone in their workplace. Most of the individuals interviewed experienced a range of reactions from people at work but most reactions were reported to be positive and supportive. More individuals with HIV infection than cancer reported examples of negative or unpleasant experiences in their interactions with others. Sixty-four percent of individuals with cancer reported receiving accommodations on their job, as compared to 50 percent of people who were HIV positive. Despite similarities in the symptoms they experienced, the manifestation of these two illnesses was described differently by participants. Strategies are suggested for individuals concerning the decision to disclose, the disclosure strategy, requesting accommodations, and rights and resources. (DB)

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# WORKING IT OUT: WORKPLACE EXPERIENCES OF INDIVIDUALS WITH HIV AND INDIVIDUALS WITH CANCER

By

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INSTITUTE FOR COMMUNITY INCLUSION

# Research to Practice

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## Working it Out: Workplace Experiences of Individuals with HIV and Individuals with Cancer

*by Sheila Lynch Fesko*

### Introduction

Advances in the treatment of cancer and HIV infection are allowing individuals with these illnesses to continue working or return to work in greater numbers than previously possible. The nature of these illnesses and their treatments have implications for the workplace as well as for the individual employee. While both cancer and HIV infection are identified in the Americans with Disabilities Act as disabilities that are protected from discrimination, individuals continue to feel anxiety at talking about their illness in the workplace and requesting necessary accommodations. This brief describes the experiences of individuals with either illness, the similarity and differences in their experiences and provides strategies recommended by participants in the areas of disclosure, support and personal advocacy in the workplace.

### Participants

Individuals with cancer and individuals with HIV infection were recruited to participate in a forty five minute interview to discuss their employment related experiences and concerns. Thirty two individuals were interviewed, 18 with HIV infection and 14 with cancer. Eighty-eight percent of the sample were between the ages of 30 and 50 and all participants were working or had been working in the previous six months. With participants consent, most interviews were tape recorded. The tapes were then transcribed and the content was coded to identify consistent themes across subjects.

### Findings

**The decision to tell their supervisor and/or co-workers about their health status varied substantially between individuals with HIV infection and those with cancer. All of the study participants with cancer disclosed to their employer and co-workers. In contrast, only a third of the individuals with HIV infection told everyone in their workplace.**

- Twenty-seven percent of the individuals with HIV infection reported that they did not tell anyone in their workplace. Women were less likely than men to fully disclose their health status in the workplace. Seventy-seven percent of the women disclosed selectively or not at all, compared to 55% of men who did the same.
- Confidentiality was critically important to individuals with HIV infection. Approximately one third of these individuals told people selectively in their department and they placed a strong emphasis on privacy. Several people with cancer reported that after they told their supervisor, the supervisor told everyone else in the department. None of these individuals with cancer reported being concerned that their confidentiality was violated.

**Most of the individuals interviewed experienced a range of reactions from people at work, but the majority of people, both those with HIV infection and those with cancer, experienced positive and supportive reactions. More individuals with HIV infection reported examples of negative or unpleasant experiences in their interactions with others.**

- Seventy-eight percent of the people who had cancer indicated that they had had a positive or supportive reaction from co-workers and supervisors. Fifty percent of the people with HIV infection who disclosed their status to others at work reported a positive response.
- Forty-four percent of individuals with HIV infection who disclosed their status reported examples of negative experiences with co-workers or supervisors, as compared to 35% of those individuals who had cancer. Examples of negative interactions were individual's being the subject of gossip or being shunned by co-workers.
- Four individuals with HIV infection and two people with cancer experienced what they considered discriminatory treatment such as being demoted or let go from their job. Both of the individuals with

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cancer were pursuing legal action, but this was not the case for individuals with HIV infection.

- The nature of the cancer diagnosis did not substantially impact the reactions individuals received from co-workers or supervisors. Individuals whose diagnosis had a positive prognosis were as likely to receive fearful and distancing response as individuals with a more life threatening diagnosis.

**Due to the nature of both HIV infection and cancer, individuals who had these diagnoses required adjustments to their work routines. Sixty-four percent of individuals with cancer reported receiving accommodations on their job, as compared to 50% of people who were HIV+.**

- Individuals with cancer typically received two or three accommodations, while a majority of the individuals with HIV infection received one.
- The accommodation most frequently received by individuals with HIV infection was schedule modification for medical appointments.
- For people with cancer the most frequently received accommodations were medical leaves of absence, flexible schedules and changes in workload.

**Despite similarities in the symptoms they experienced, the manifestation of these two illnesses was described differently by participants in this study.**

- Individuals with HIV infection typically became aware of their diagnosis when they were healthy or experiencing health concerns that required little immediate intervention.
- People who were diagnosed with cancer frequently needed to begin treatment immediately. While the emotional toll of being diagnosed with either diseases was substantial, individuals with cancer typically began treatment within a week of their diagnosis and had less options about disclosing their illness to their employer.

## Discussion

Individuals with cancer and those with HIV infection share many of the same experiences in dealing with a significant medical concern in the workplace, but the nature of their illness and societal responses to each diagnosis create some differences. Individuals with HIV infection frequently indicated that the stigma associated with the disease caused them to be reticent in disclosing to others. Stigma was infrequently raised as a concern for people with cancer and this difference is reflected in their willingness to share their diagnosis with others. With this free disclosure of their health status, individuals with cancer reported that they felt that they received more support than they would have otherwise received. They received more accommodations than individuals with HIV infection and in some cases received more accommodations than they had requested. This greater number of accommodations may be related to the severity of physical symptoms some individuals with cancer experienced.

Although both people with cancer and those with HIV infection experienced some negative reactions or discriminatory behavior, only people with cancer pursued legal avenues to address these concerns. Twice as many people who were HIV+ reported feeling they had been treated unfairly or had been discriminated against, but none of them contacted lawyers. It was unclear why this difference existed between people with cancer and those with HIV infection. It may be that the people with cancer were better educated about their rights or felt they would get more support through the courts than did individuals with HIV infection. The stigma that continues to be associated with the HIV virus may also be a barrier for individuals pursuing their legal rights. There is less of an expectation of support by individuals with HIV infection and this may carry to their expectations of the court system.

## Implications

Study participants suggest the following strategies in dealing with a significant medical concern in the workplace.

### Decision to Disclose

The decision to disclose HIV status or a cancer diagnosis is a personal choice that needs to be made with careful consideration. Participants felt there was no right or wrong answer to the question of disclosure. Individuals might consider some of the following factors as decision are made.

- Consider the culture of the work environment. The individual needs to judge whether people are typically supportive of each other and share personal information or whether everyone is very focused on work and there is limited sharing.
- Identify risk factors that are faced at the work site.



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One suggestion made by an individual with HIV infection was to test out the work environment by raising the issue of HIV infection in a more neutral way, possibly in relation to a movie or a charitable event, and assess the reactions of others.

- There are risks to disclosing, but there are also risks or problems associated with not disclosing one's health status. By not telling supervisors and co-workers, some study participants were not able to get accommodations that they were legally entitled to and which might have allowed them to continue working. The stress of not telling was also reported by some interviewees as being problematic and causing them to feel isolated at work.
- Individuals with HIV infection suggested, when possible, individuals should not tell people at work for at least a year after being diagnosed. One woman described needing this year to adjust to her diagnosis and to accept it herself before she could decide to share it with others.

## Disclosure Strategy

If any individual chooses to discuss they should develop a workplace strategy prior to telling others. The following features should be considered in this strategy.

- Identify one's personal style and comfort in sharing personal information. Assess whether to tell select people or share more openly.
- Script a disclosure statement and practice it until comfortable presenting the information. Focus on positive contributions rather than limitations the illness may have created. Avoid medical jargon.
- Decide on the manner in which confidentiality should be handled and discussed with supervisors. Unless it is clear that the individual wants to keep this information confidential, the supervisor might assume it is information they can share.
- Have one person at the workplace serve as an information source for all other co-workers. Several survey participants preferred to keep one person up to date on their treatment and health status and have them share the information, rather than answering questions from many people throughout the day.
- Clearly articulate what actions would be supportive. Some individuals feel more support in being able to talk about their diagnosis and have people ask them about their treatment. They should indicate that preference. If the individual would prefer that people not raise it unless they bring it up, they should let co-workers and supervisors know that.
- Be prepared to deal with the fear and anxiety that may be expressed by supervisors or co-workers. Study participants indicated this was a common first reaction. As much as possible, have information ready about prognosis and treatment in order to respond to concerns expressed by others.

## Requesting Accommodations

- Become educated about the company's policies concerning medical leave and accommodation as well as federal law.
- Be direct and honest when asking for an accommodation, change in schedule or leave of absence. To encourage a more positive response from supervisors and co-workers, the individual should be clear about needs, realistic about time required and, if possible, suggest a plan to cover responsibilities.
- Be prepared for negotiation regarding accommodations to take some time. It is likely that the supervisor has not previously dealt with this issue. The supervisor's hesitation may be based on concern or a lack of knowledge rather than resistance to meeting individual needs.
- Document requests for accommodation and outcomes.
- If accommodations are not responded to in a timely manner or are not implemented, consider contacting a representative from Human Resources to help with the negotiation.

## Rights and Resources

Knowledge about legal rights and resources was viewed as an important component of an individual's workplace strategy, but many study participants indicated that it was challenging to know where to find this information. The following resources are available to individuals who are dealing with a health concern at work.

- The Family and Medical Leave Act of 1993 protects individuals who need to take time off of work because of health concerns. Under this law most employers must grant up to three months leave with no risk to the individual's job. For additional

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information about this law, individuals may want to refer to A Q & A Guide to FMLA published by the Women's Legal Defense Fund. (1875 Connecticut Ave. NW, Suite 710, Washington D.C., 20009; $3.50)

- Concern about maintaining health insurance was raised by many study participants. The Health Insurance Portability and Accountability Act protects individuals from being denied health insurance because of pre-existing conditions. For more information about this law, individuals can receive the Questions & Answers: Recent Changes in Health Care Law from the Department of Labor at 1-800-998-7542. The publication is also available on the Internet at www.dol.gov/dol/pwba.
- The Americans with Disabilities Act (ADA) protects individuals with disabilities or significant medical concerns from discrimination. The Mid-Atlantic ADA Information Center (800-949-4232) distributes federally-approved ADA regulations and materials. An additional resource for materials on ADA is the Industrial and Labor Relations program on Employment and Disability at Cornell University (607-255-2906).
- The Job Accommodation Network (JAN) is a national resource that assist individuals and employers dealing with workplace accommodation needs. (800-JAN-7254 or 800-ADA-WORK). The JAN website is http://janweb.icdi.wvu.edu/
- For individuals with cancer, the National Coalition for Cancer Surviworship has a booklet called Working It Out: Your Employment Rights as a Cancer Survivor. This booklet can be ordered at NCCS, 1010 Wayne Avenue, Seventh Floor, Silver Springs, MD 20910. (301-650-8868)

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**This publication will be made available in alternate formats upon request.**

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